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Patient, Partner and Physician

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13. ABSTRACT (Maximum 200 Words) "Treatment Decisions in Localized Prostate Cancer: Patient, Partner and Physician," is a project that aims to develop and refine an innovative new model of prostate cancer decision making, that will form the foundation of a research and clinical program to understand, support and improve decision making in prostate cancer. This project is using a cross-sectional survey to explore the role of the patient, partner and physician in treatment decisions and to examine the effect of preferences, perceived preferences, and actual preferences on treatment decisions, decision satisfaction and decision process. Many valuable steps have been taken in the first year of this grant, including the development of a pilot questionnaire, administration of the pilot questionnaire, development of the protocol for the study and development of patient, spouse and physician questionnaires. Enrollment for the study began in November, 2000.				
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Introduction

"Treatment Decisions in Localized Prostate Cancer: Patient, Partner and Physician," is a project that aims to develop and refine an innovative new model of prostate cancer decision making, that will form the foundation of a research and clinical program to understand, support and improve decision making in prostate cancer. We use a cross-sectional survey of patients, their spouses and their physicians to explore the role of the patient, partner and physician in treatment decisions, and to examine the effect of preferences, perceived preferences, and actual preferences on treatment decisions, decision satisfaction and decision process. By characterizing the role of the partner and the presence of significant misperceptions in the triad, and explicating the process of decision making under conditions of routine care, results of this project will serve as a basis for launching a research program in prostate cancer decision making. The guiding assumption of this work is that facilitation of communication and identification and resolution of misperceptions in the patient-partner-physician triad will improve patient satisfaction in decision making concerning localized prostate cancer.

Body

Task 1: Focus group discussions

We attended the bimonthly prostatectomy clinic (a session for prostate cancer patients to learn what to expect with their upcoming surgery to remove their prostate) at the University of Pennsylvania on two occasions to learn about the prostate cancer patients' experiences.

Task 2: Development of Survey Instruments

In early discussions about the study, we decided to switch the study instrument from phone interviews to mailed surveys. Our reasoning for this change was the expectation of a greater response rate and more honest responses to a survey than to a phone interview.

In addition to the information gathered in Task 1, numerous steps were taken to collect information for developing the survey instruments for this study.

We gathered information from an extensive literature review of existing studies of decision making in localized prostate cancer, and also from a literature review of research on decision making factors for patients with other types of cancer.

We conducted numerous discussions with several of the nurses and physicians who care for the prostate cancer patients in our sample population. These individuals interact with the patients from the time the patients are diagnosed with cancer (if not before) to the time they begin treatment. Therefore, they were able to provide us with much insight into the patients' experiences as they learn of their diagnosis, explore their treatment options, and make a treatment decision.

With this information, we developed a pilot survey (Appendix A) which was administered to prostate cancer patients attending a prostatectomy clinic (a session to learn what to expect with their upcoming surgery to remove their prostate) at the University of Pennsylvania. The purpose of this pilot survey was to learn about the process from diagnosis to treatment from the patient's perspective.

From this small-scale pilot study (involving 5 prostate cancer patients), we learned about the steps of the process the men underwent. All of the men were first told of their treatment options by the urologist who did their biopsy and they were told of these options at the same appointment during which they learned their biopsy results. Four of the 5 men had a spouse or another close family member present when they learned about their treatment options. Two of

the 5 reported that their urologist recommended that they get a radical prostatectomy, and 3 of the men report speaking to a radiation oncologist before making their treatment decision. Of the 3 men who spoke to a radiation oncologist, 1 reported that his urologist recommended doing so. Three of the 5 men reported first thinking seriously about their treatment options upon learning of their positive diagnosis of prostate cancer. The fourth man first thought seriously about his options when he went for his prostate biopsy (the diagnostic test for prostate cancer) and for the fifth, it was some time after he received his results. Two of the 5 men reported making their treatment decision on their own, and 3 reported making the decision with their spouse. Each of the men also described what they did to gather information about treatment options before making their decision.

We consolidated all of the information we gathered in the steps described above to write preliminary patient, partner and physician surveys. These preliminary surveys were sent to prostate cancer patients and their spouses for feedback and suggested revisions. Participants were asked to note any omissions from the survey and any questions that they found confusing. Before and after comments were incorporated into the survey drafts, numerous drafts of the surveys were critically reviewed by each investigator on the grant and by other individuals who have expertise in research and survey design. These revisions required numerous project group meetings. A final patient survey, partner survey, and doctor survey has now been developed (Appendix B, C and D).

Task 3: Preparation of Interim Reports and Manuscripts

The annual report is provided here.

Task 4: Cross-sectional survey

Identification and recruitment of subjects

Through numerous project meetings and extensive discussions with the physician and nurse providers of the prostate cancer patients in our sample, a system for identifying and recruiting each newly diagnosed localized prostate cancer patient was developed. At each hospital in our sample, we learned about the process that patients undergo from the point of learning their prostate cancer diagnosis to beginning treatment. With this information, we were able to develop a system at each hospital for identifying new prostate cancer patients, informing them of our study (and their option to decline participation), obtaining consent in an oral consent

interview, and having the patient, the patient's spouse and physician complete their respective surveys.

Site 1: Veteran's Affairs Medical Center (VAMC)

At the VAMC, new prostate cancer patients are identified when they arrive for their appointment to learn their prostate biopsy results. At the end of the appointment, their physician hands them a letter (Appendix E) from us informing them of the study and giving them a phone number to call if they would like to decline participation. At this point, the physician completes the study's physician survey that examines his/her interactions with that patient. One week later, we send the patient and his spouse (if applicable) a letter and consent form for both the patient and the spouse's participation in the study. After allowing for sufficient time to pass for the consent forms to arrive in the mail, we call the patient to conduct an oral consent interview with him and his spouse. When the consent interview is complete, if the patient and/or his spouse have consented to participate, we mail the patient and spouse a survey packet. If the surveys are not returned within 3 weeks, we place a follow-up call to gently remind the subjects to please return their surveys.

Site 2: Hospital of the University of Pennsylvania (HUP)

The patients of two physicians at HUP are included in this study.

Physician 1: The nurse coordinator maintains a list of names of patients with positive biopsy results. Patients are added to the list when they call the nurse coordinator and receive news of their prostate cancer diagnosis. A letter informing the patients of our study and the phone number to call to decline participation is included in a packet of information (about prostate cancer and treatment options) sent to each patient. Shortly thereafter, we send the patient and his spouse (if applicable) a letter and consent form for both the patient and the spouse's participation in the study. After allowing for sufficient time to pass for the consent forms to arrive in the mail, we call the patient to conduct an oral consent interview with him and his spouse. When the consent interview is complete, if the patient and/or his spouse have consented to participate, we mail the patient and spouse a survey packet. If the surveys are not returned within 3 weeks, we place a follow-up call to gently remind the subjects to please return their surveys.

Physician 2: The protocol for this physician was identical to that for Physician 1, with two exceptions. (1) This physician's patients were identified when patients called in to

schedule a bone scan appointment. All newly diagnosed prostate cancer patients receive at this hospital site. (2) We mailed the patient the letter informing him of our study and giving them a phone number to call to decline participation, rather than the letter being included in a packet of information already sent to the patient. The rest of the protocol was identical to that for physician 1.

Development of data management system

A data management system was developed for both contact information and survey data for the subjects in this study. This system enables us to follow each subject through each step of the study: diagnosis, obtaining a letter informing the patient of the study and giving them the opportunity to decline participation, being sent the study consent forms in the mail, completing the oral consent interview over the phone, being sent the study survey, returning the survey, and obtaining the physician's completed survey.

Enrolling subjects

In November 2000, we began identifying and enrolling subjects in our study. To date, we have identified 43 patients at our two hospital sites combined. Two patients have been excluded because of mental disorders, and 6 patients have declined participation at the point of the consent call, before they were sent a study survey. Of the 17 patients with whom we successfully contacted by phone for a consent interview and who agreed to participate, 6 have returned their completed study questionnaires.

Key Research Accomplishments

- Discussions with prostate cancer patients and their health care providers
- Literature review
- Pilot survey
- Development of survey instruments
- Development of system of identification and recruitment of subjects
- Development of data management system
- Enrollment of prostate cancer patients in the study
- Initiation of data collection

Reportable Outcomes

To date, there are no reportable outcomes for this study.

Conclusions

The past year has been productive and informative for this study. From discussions with the involved parties, literature searches and a pilot study, we have gathered much information, about the decision making process for men newly diagnosed with localized prostate cancer. We decided to change the study instrument from a phone interview to a mailed survey. We have developed study instruments: surveys for patients, their spouses, and their doctors, and determined the most effective and feasible approach to identifying and recruiting subjects at each hospital site. We have developed a data management system for monitoring and recording information about each step of the study protocol. We have begun enrollment of subjects into our study and some subjects have returned completed surveys.

Appendix A: Pilot survey

University of Pennsylvania
Prostate cancer decision making questionnaire

We are researchers at the University of Pennsylvania interested in learning about the treatment decision making process of men diagnosed with prostate cancer. Answering the questions below indicates that you are willing to participate in this research.
If you have any questions, please call Andrea Gurmankin at 215 898 9722.

1. Please check the box that best describes you:

- ☐ I came to HUP urology AFTER being diagnosed with prostate cancer.
- ☐ I was diagnosed with prostate cancer by HUP urology
- ☐ Other (**Please explain**):

2. Who first told you about your treatment options for prostate cancer?

- ☐ My primary care doctor/general practitioner
- ☐ The urologist who did my biopsy
- ☐ The urologist who I went to after learning of my prostate cancer diagnosis
- ☐ A friend/acquaintance who knows about prostate cancer
- ☐ Other (**Please explain**):

3. When did you first learn about your treatment options for prostate cancer?

- ☐ At the same appointment during which I learned about my biopsy results
- ☐ At the same appointment during which I learned of my abnormal PSA test.
- ☐ From a friend/acquaintance before my biopsy
- ☐ From a friend/acquaintance after I got my biopsy results
- ☐ Other (**Please explain**):

4. Was your spouse or another close family member present when you first learned about your treatment options?

☐ Yes

☐ No

5. Did your urologist recommend that you get a radical prostatectomy?

☐ Yes

☐ No

6. Did you speak to a radiation oncologist before making your decision?

☐ Yes

☐ No

7. If you saw a radiation oncologist, did that doctor recommend radiation therapy?

☐ Yes

☐ No

☐ I didn't see a radiation oncologist

8. When did you first start seriously thinking about your treatment options and trying to make a treatment decision?

☐ When I first got my abnormal PSA test/ abnormal exam / other reason for suspicion that I had prostate cancer (other than a positive biopsy)

☐ When I went to a urologist to get my prostate biopsy

☐ After I got my biopsy but before I got the biopsy results

☐ When I got my biopsy results

☐ After I got my biopsy results (**please explain** when after you got the results you started thinking about your options and trying to make a decision):

9. To the best of your ability, please describe when you made your final decision about which treatment option to take. (Here are some sample answers to give you an idea of what we are looking for: At the doctor's appointment when I found out the biopsy results, While talking to my spouse the day after learning the biopsy results, Before getting the biopsy, After talking to a radiation oncologist, my spouse, and others about a week after learning the biopsy results, etc).

(**Please explain**-continue to the top of the next page for more space):

10. Do you have a spouse?

☐ Yes

☐ No

If YES to #10, please respond to #10a and #11.

10a. How much did you and your spouse discuss your treatment options and their pros and cons

☐ Not at all

☐ A little

☐ Some

☐ A lot

11. Did you make your final decision on your own, or with your spouse?

☐ On my own

☐ With my spouse

☐ Other (**Please explain**):

We may want to contact you by phone in the next few weeks to ask you a few more questions about your experience. If you do not want us to contact you, please check the appropriate box below. If it is okay for us to contact you, please check the appropriate box and provide your name, phone number and the best time to call:

☐ Please do not call me

☐ It is okay to call me.

Name Mr. Ms. Mrs. Dr. _____

My phone number (_____) _____

Best time to call _____

Appendix B: Patient survey

**MEN'S HEALTH CARE
DECISION MAKING
STUDY**

**FOR YOU
TO COMPLETE**

Thank you very much for your help.

Please return in the enclosed envelope.

Instructions:

This questionnaire asks about your experiences with the diagnosis of prostate cancer and deciding on a treatment. Your answers will be strictly confidential. It is extremely important that you follow these guidelines when filling out this questionnaire:

1. Please fill it out and return it to us AFTER you have made your prostate cancer treatment decision but BEFORE you have begun treatment for prostate cancer (i.e. surgery, radiation, seed implants, etc).
2. Please fill out this questionnaire without any communication between you and your partner. We are interested in YOUR thoughts, even on the questions that ask about your partner. So please do not get any information or input from your partner while filling out the questionnaire.
3. Please answer every question to the best of your ability, even if you are unsure of your response.

If you have any questions, please feel free to contact Genevieve Fitzgerald at 215 573-7275. Thank you in advance for your participation.

Date you are filling out this questionnaire: ____/____/____

Who is your urologist? _____ (Your doctor will never see your responses)

Part A. The first set of questions asks about your treatment decision.

- 1) Which of the following possible treatments for prostate cancer have you heard of? (*check all that you have heard of*)
 - ☐ Surgery (Radical prostatectomy- procedure where they remove the prostate)
 - ☐ Radiation therapy
 - ☐ Seed implants (Brachytherapy)
 - ☐ Hormone therapy
 - ☐ Watchful waiting (No treatment, but getting regular blood tests to check on the status of the cancer)
- 2) Which treatment have you chosen? (*check all that apply*)

<input type="checkbox"/> Surgery	<input type="checkbox"/> Radiation therapy	<input type="checkbox"/> Watchful waiting
<input type="checkbox"/> Seed implants	<input type="checkbox"/> Hormone therapy	<input type="checkbox"/> Other (Please explain):
- 3) Approximately when did you make your final decision about what treatment you would get for your prostate cancer? This includes deciding on watchful waiting. (*We understand it may be difficult to remember the date, so please just give your best estimate*).

____/____/____

4) How important were each of the following things in your decision:	Extremely important	Very important	Somewhat important	Slightly important	Not at all important
a) possibility of impotence (inability to get or maintain an erection)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) possibility of incontinence (trouble controlling your urine)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) risks of anesthesia (the medicine given to patients to put them to sleep during surgery)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) feeling certain that the cancer is completely gone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) keeping my body intact	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) avoiding losing my identity as a man	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) desire to live as long as possible	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) cost of the treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i) discomfort of the treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j) time it takes to get the treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k) how long it takes to recover from the treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l) "track record" of the treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m) how quickly the treatment works	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
n) my urologist's opinion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
o) my primary care doctor's opinion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
p) my partner's opinion (<i>leave blank if you don't have a partner</i>)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
q) another family member's opinion (how are you related to this person?): _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
r) opinion of a friend or acquaintance who has or has had prostate cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
s) information from other sources (what sources):	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
t) other (please explain):	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- 5) Now please circle the letter beside the one factor listed **above in question 4** that was the **most important factor** in your treatment decision.

- 6) What have you done to get information about your treatment options (*check all that apply*)

☐ Speak to my doctor

Which doctor(s)? ☐ Urologist ☐ Primary care doctor ☐ Other

☐ Speak to friend/acquaintance who is a doctor

☐ Speak to prostate cancer survivors

☐ Get information on the internet

☐ Get information in books/medical journals

☐ Other (Please explain below where else you got information):

- 7) Based on the information you have, what do you think your chance of impotence is?
(Please give a number between 0% and 100%). _____

- 8) Based on the information you have, please rate what you think your chance of impotence is (*circle one number*):

1	2	3	4	5
Not at all likely	Slightly likely	Somewhat likely	Very likely	Extremely likely

- 9) Based on the information you have, what do you think your chance of incontinence is?
(Please give a number between 0% and 100%). _____

- 10) Based on the information you have, please rate what you think your chance of incontinence is (*circle one number*):

1	2	3	4	5
Not at all likely	Slightly likely	Somewhat likely	Very likely	Extremely likely

- 11) Based on the information you have, what do you think your chance of death is? (*Please give a number between 0% and 100%*). _____

- 12) Based on the information you have, please rate what you think your chance of death is (*circle one number*):

1	2	3	4	5
Not at all likely	Slightly likely	Somewhat likely	Very likely	Extremely likely

- 13) Based on the information you have, what do you think your chance of cure is? (*Please give a number between 0% and 100%*). _____

- 14) Based on the information you have, please rate what you think your chance of cure is (*circle one number*):

1	2	3	4	5
Not at all likely	Slightly likely	Somewhat likely	Very likely	Extremely likely

Part B. The next questions ask about when you were first diagnosed with prostate cancer.

- 1) Which doctor did you **first** speak to about whether you should get a biopsy to look for prostate cancer?
☐ My primary care doctor ☐ A friend/acquaintance who is a doctor
☐ A urologist ☐ Other (Please explain):

- 2) Why did you have this conversation about getting a biopsy? (*Check **all** that apply*)
☐ I had an abnormal PSA test (blood test)
☐ I had an abnormal rectal exam (the doctor felt something suspicious when he felt my prostate)
☐ I had symptoms from my prostate (trouble passing urine, blood in urine, incontinence)
☐ I was concerned about a history of prostate cancer in my family
☐ Other (Please explain):

- 3) Which doctor did you **first** speak to about your treatment options for prostate cancer?
☐ My primary care doctor ☐ A friend/acquaintance who is a doctor
☐ A urologist ☐ Other (please explain):

- 4) When did this conversation occur?
☐ during an appointment or conversation **before I got my biopsy results**
☐ **during** the same appointment or conversation in which I **got my biopsy results**
☐ during an appointment or conversation at some point **after I got my biopsy results**
☐ Other (please explain):

- 5) Was your partner present during this conversation?
☐ Yes ☐ No ☐ I have no partner

If the first time you talked to a doctor about treatment options was NOT with a urologist:

6)

a) When was the main conversation you had with a urologist about your treatment options?

- ☐ during an appointment or conversation **before I got my biopsy results**
☐ **during** the same appointment or conversation in which I **got my biopsy results**
☐ during an appointment or conversation at some point **after I got my biopsy results**
☐ Not applicable
☐ Other (please explain):

b) Was your partner present during this conversation about treatment options with the urologist?

- ☐ Yes ☐ No ☐ I have no partner

Part C. The next set of questions asks more about your conversation with your urologist about treatment options. If you have not yet spoken to your urologist about treatment options, please skip to Part D.

1) Approximately what was the date of your conversation with your urologist about your treatment options (please give your best estimate) ____/____/____

2) About how much time did you spend talking with the urologist about your treatment options? (please give your best estimate) ____ minutes

3) Would you have preferred to spend more or less time talking with the urologist? (Please circle a number below)

1	2	3	4	5
Much less	A little less	Neither more nor less	A little more	Much more

4) Did the urologist →

- | | | |
|---|------------------------------|-----------------------------|
| a) mention the option of getting surgery? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| b) mention the option of getting radiation therapy? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| c) mention the option of getting seed implants? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| d) mention the option of getting hormone therapy? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| e) mention the option of watchful waiting? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |

5) Would you have preferred more or less information from the urologist? (Please circle a number below)

1	2	3	4	5
Much less	A little less	Neither more nor less	A little more	Much more

6) If you had any questions for the urologist, did you feel free to ask your questions?

- ☐ I did not have any questions
- ☐ Yes
- ☐ No → Why not?:

7) Did your urologist give you **information about each of the following** things using **numbers** (for example, "a 2% chance") or **words** (for example, "a very small chance")?

a) **Chance of impotence:**

- ☐ No numbers/only words
- ☐ Only numbers/no words

- ☐ Some numbers/some words
- ☐ No information given about chance of impotence

b) **Chance of incontinence:**

- ☐ No numbers/only words
- ☐ Only numbers/no words

- ☐ Some numbers/some word
- ☐ No information given about chance of incontinence

c) **Chance of death:**

- ☐ No numbers/only words
- ☐ Only numbers/no words

- ☐ Some numbers/some word
- ☐ No information given about chance of death

d) **Chance of cure:**

- ☐ No numbers/only words
- ☐ Only numbers/no words

- ☐ Some numbers/some words
- ☐ No information given about chance of cure

8) Did the urologist recommend a particular treatment to you? ☐ Yes ☐ No

If yes →

a) What was the urologist's treatment recommendation?

b) How strong was the urologist's recommendation? (*circle one number*)

1	2	3	4	5
Not at all strong	Slightly strong	Somewhat strong	Very strong	Extremely strong

9) Did you want the urologist to provide a recommendation? ☐ Yes ☐ No

Please explain why you did or did not want the urologist to provide a recommendation:

- 10) Did the urologist suggest that you speak to a radiation oncologist? ☐ Yes ☐ No
- 11) Did you speak with a radiation oncologist? ☐ Yes ☐ No
- 12) Did you get a second opinion from another urologist? ☐ Yes ☐ No
- 13) Which of the following best describes how the decision about your prostate cancer treatment was made?
- ☐ My urologist made the final decision
 - ☐ My urologist made the final decision after seriously considering my opinion
 - ☐ My urologist and I shared responsibility for the final decision.
 - ☐ I made the final decision after seriously considering my urologist's opinion.
 - ☐ I made the final decision on the basis of the facts I learned from my urologist and elsewhere, without considering my doctor's opinion.

Part D. The next questions ask about your thoughts about different treatments and side effects.

1) How concerned are <u>you</u> about experiencing:	Extremely concerned	Very concerned	Somewhat concerned	Slightly concerned	Not at all concerned
a) incontinence (trouble controlling your urine)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) impotence (trouble getting or maintaining an erection)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) risks of anesthesia (the medicine given to patients to put them to sleep during surgery)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- 2) Which treatment do **you** think has the best chance of cure for you?
- ☐ Surgery ☐ Radiation therapy ☐ Hormone therapy
 - ☐ Watchful waiting ☐ Seed implants ☐ I don't know
 - ☐ They all have the same chance of cure
- 3) Which treatment do **you** think has the best chance of avoiding side effects?
- ☐ Surgery ☐ Radiation therapy ☐ Hormone therapy
 - ☐ Watchful waiting ☐ Seed implants ☐ I don't know
 - ☐ They all have the same chance of avoiding side effects

Please continue to the next page →

Part E. Next we ask about what you think **YOUR PARTNER** thinks about different treatment options. We also ask about the discussions you two had about your options. *If you do not have a partner, skip to Part F.* Please remember to respond without input from your partner.

1) How concerned <u>do you think your partner is about you experiencing:</u>	Extremely concerned	Very concerned	Somewhat concerned	Slightly concerned	Not at all concerned
a) incontinence (trouble controlling your urine)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) impotence (which is the inability to attain or maintain an erection)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) the risks of anesthesia (the medicine that they give to patients to put them to sleep during the surgery)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- 2) Which treatment do **you think your partner** thinks has the best chance of cure for you?
- ☐ Surgery ☐ Radiation therapy ☐ Hormone therapy
☐ Watchful waiting ☐ Seed implants
☐ I don't know what my partner thinks
☐ They all have the same chance of cure
- 3) Which treatment do **you think your partner** thinks has the best chance of avoiding side effects?
- ☐ Surgery ☐ Radiation therapy ☐ Hormone therapy
☐ Watchful waiting ☐ Seed implants
☐ I don't know what my partner thinks
☐ They all have the same chance of avoiding side effects
- 4) If it had been up to **your partner**, which treatment do you think she would have chosen for you?
- ☐ Surgery ☐ Radiation therapy ☐ Hormone therapy
☐ Watchful waiting ☐ Seed implants
☐ I don't know what my partner would have chosen
☐ Other (please explain):
- 5) How does **your partner** feel about the treatment that was chosen?
- ☐ Insisted that I get it ☐ Opposed the decision
☐ Supported the decision ☐ Insisted that I not get it
☐ I don't know how my partner feels
☐ Other (please explain):

- 6) How often did you and your partner discuss your treatment options? *(please circle a number below)*

1	2	3	4	5
Never	Seldom	Now and then	Quite often	Very often

- 7) Would you have preferred to discuss your treatment options with your partner more or less? *(please circle a number below)*

1	2	3	4	5
Much less	A little less	Neither more nor less	A little more	Much more

If you responded "never" to question 6, skip to question 11. Otherwise, continue to question 8.

- 8) When you had these discussions about treatment options, who initiated them?
☐ Me ☐ My partner ☐ We both initiated some of the discussions.

- 8) How satisfied were you with those discussions? *(please circle a number below)*

1	2	3	4	5
Very dissatisfied	Somewhat dissatisfied	Neither satisfied nor dissatisfied	Somewhat satisfied	Very satisfied

- 10) How often did you and your partner get into a disagreement or conflict over the issue of which treatment to choose? *(please circle a number below)*

1	2	3	4	5
Never	Seldom	Now and then	Quite often	Very often

- 11) How strongly did you want your partner's opinion to be factored into your treatment decision? *(circle a number below)*

1	2	3	4	5
Not at all	A little	Somewhat	Very	Extremely

Please continue to the next page →

The following statements focus on the way your partner deals with the fact that you have prostate cancer. Please indicate to what extent your partner does or does not act in the ways described.

	Never	Seldom	Now and then	Quite often	Very often
12) my partner tries to discuss it with me openly	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13) my partner asks me how I feel	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14) when something bothers me, my partner tries to discuss the problem	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15) my partner is full of understanding towards me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16) my partner makes me feel that I'm not alone in this	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17) my partner tries to persuade me to follow the doctor's instructions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18) my partner tries to hide his or her worries about me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19) my partner tries to act as if nothing is the matter	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20) my partner gives in when I make an issue of something	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21) my partner just waves my worries aside	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22) my partner does everything to prevent me from thinking about my disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23) my partner can't endure me being concerned and acts as if she doesn't notice my worries	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24) my partner takes over as much of my work as possible	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please continue to the next page →

Part F. This set of questions asks about your feelings of conflict over your prostate cancer treatment decision. The statements below are things that some people say when they have just made a difficult decision. Thinking about decision, please check the box that best matches how much you agree with each statement.

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
1) I feel I have made an informed choice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2) My decision shows what is most important for me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3) I expect to stick to my decision.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4) I am satisfied with my decision.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5) This decision was hard for me to make	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6) I was unsure what to do in this decision	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7) It was clear what choice was best for me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8) I am aware of the choices I have to manage my prostate cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9) I feel I know the benefits of the treatments for prostate cancer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10) I feel I know the risks and side effects of treatment for prostate cancer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11) I need more advice and information about the choices.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12) I know how important the benefits of the treatment for prostate cancer are to me in this decision.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13) I felt pressure from others in making this decision.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14) I had the right amount of support from others in making this decision.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Part G. The next questions ask about your background.

- 1) What is your age? _____ years
- 2) What is your race?
☐ African-American ☐ Caucasian ☐ Hispanic
☐ Asian-American ☐ Other (please specify) _____
- 3) What level of education have you completed? (*Circle one number*)
9 10 11 12 13 14 15 16 17 18 19 20 21+
high school college graduate school
- 4) Which of the following conditions have you had in the past 12 months?
(*check all that apply*)
☐ high blood pressure ☐ heart trouble
☐ diabetes ☐ emotional or mental illness
☐ stroke ☐ chronic bronchitis
☐ asthma ☐ arthritis or rheumatism
☐ cancer (other than prostate) ☐ epilepsy
☐ chronic nervous trouble ☐ tuberculosis
☐ hernia or rupture ☐ chronic liver problem
☐ drinking problems or alcoholism ☐ chronic gallbladder trouble
☐ stomach ulcer or duodenal ulcer
- 5) Are you currently experiencing impotence? ☐ Yes ☐ No
- 6) Are you currently experiencing incontinence? ☐ Yes ☐ No
- 7) Do you currently have health insurance? ☐ Yes ☐ No ☐ Not sure
- 7a) *If yes* ➤ please check the type of plan that best describes your current health insurance:
☐ Fee-for-service plan where you can go to any doctor or hospital
☐ HMO where your primary care doctor refers you to specialists
☐ PPO where you can go to any doctor or hospital on a list without getting a referral
☐ I don't know which type of plan I have

Part H. This section asks about your relationship with your partner. *If you do not have a partner, skip to Part I.*

Most people have some disagreements in their relationships. Below is a series of issues. We'd like you to tell us of any disagreement experienced between you and your partner over each of these issues in a typical month (this past month may not have been typical for you, since you were just diagnosed with prostate cancer). So for each issue, please tell us in a typical month, how much you have agreed or disagreed.

In a typical month, my partner and I have		Always agreed	Almost always agreed	Occasionally agreed	Frequently disagreed	Almost always disagreed	Always disagreed
1)	religious matters	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2)	demonstration of affection	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3)	sex relations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4)	conventionality (correct or proper behavior)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5)	making major decisions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6)	career decisions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How often do you and your partner do the following things:		All the time	Most of the time	More often than not	Occasionally	Rarely	Never
7)	discuss or consider divorce, separation, or terminating your relationship?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8)	regret that you married?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9)	quarrel?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10)	"get on each other's nerves?"	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

		Every day	Almost every day	Occasionally	Rarely	Never
11)	How often do you and your partner engage in outside interests together?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Below are some things that you and your partner might do. Please tell us how often you think they occur between you and your partner.

		More than once a day	Once a day	Once or twice a week	Once or twice a month	Less than once a month	Never
12)	Have a stimulating exchange of ideas	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13)	Calmly discuss something	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14)	Work together on a project	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

15) How often does your partner go with you to your doctors' appointments?

1	2	3	4	5
Never	Once in a while	Sometimes	Frequently	Always

16) How long have you and your partner been together? _____ years

Part I. This last section asks about your quality of life.

During the past four weeks how much of the time ...	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
1) Have you been concerned or worried about loss of muscle tone?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2) Did you have negative feelings about the way your body looks?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3) Did you avoid being seen without a shirt on?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4) Did you feel that your body was getting soft and flabby?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5) Were you concerned or worried about difficulty getting or keeping an erection?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6) Did you wish you could regain your sexual ability?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7) Did you feel frustrated about your sexual ability?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8) Did you feel despair over the loss of sexual ability?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Skip to question 15 if you do not have a partner

How true or false has each of the following statements been for you during the past four weeks?	Definitely true	Mostly true	Neither true no false	Mostly false	Definitely false
9) I felt uncomfortable when my partner wanted to hug or kiss me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10) I felt affectionate about my partner.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11) I felt that my partner was not satisfied with our sex life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12) I felt that my partner may want to turn to others for affection.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13) My partner was worried about my cancer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14) I worked hard to keep my partner from worrying about my health.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How true or false has each of the following statements been for you during the past four weeks?	Definitely true	Mostly true	Neither true no false	Mostly false	Definitely false
15) Since I've had cancer I feel that I have lost my ability to be aggressive.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16) I feel that I've lost part of my manhood.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17) I feel as if I'm going through a "change of life" like women do.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18) I feel that what I say is not taken very seriously by others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

During the past four weeks how much of the time ...	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
19) Did you feel that your cancer kept you from being the friend you wanted to be?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20) Did you feel that other people don't really understand what it's like to have prostate cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21) Did you feel that you were a bother to other people?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22) Did you worry about eventually becoming unable to take care of yourself?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23) Did you worry about your cancer, but keep it to yourself?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

24) Did you feel that others who are close to you try to hide their true feelings about your cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25) Did you feel that others think less of you because of your health problems?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26). Have you felt weak and small?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27) Have you worried about the cancer spreading?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28) Have you thought about your cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29) Have you worried about dying soon?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30) Have you been concerned about side-effects of your cancer treatment?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31) Have you felt that your cancer has given you a better outlook on your life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32) Have you felt that coping with your cancer has made you a stronger person?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33) Have you wished that you could change your mind about the kind of treatment you chose for your prostate cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How true or false has each of the following statements been for you during the past four weeks?	Definitely true	Mostly true	Neither true nor false	Mostly false	Definitely false
34) I feel that I would be better off if I had chosen another treatment for prostate cancer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35) It bothers me that other men with prostate cancer get treatment that is very different from what I will receive.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Thank you for your participation. Please mail the completed survey in the enclosed, stamped, addressed envelope.

Appendix C: Partner survey

**MEN'S HEALTH CARE
DECISION MAKING
STUDY**

**FOR YOUR
PARTNER
TO COMPLETE**

Thank you very much for your help.

Please return in the enclosed envelope.

Instructions:

This questionnaire asks about your experiences with your spouse or partner's diagnosis of prostate cancer and deciding on a treatment. Your answers will be kept strictly confidential. It is extremely important that you follow these guidelines when filling out this questionnaire:

1. Please fill it out and return it to us **AFTER** your partner's treatment decision has been made but **BEFORE** your partner has begun or undergone treatment for prostate cancer (i.e. surgery, radiation, seed implants, etc).
2. Please fill out this questionnaire without any communication between you and your partner. We are interested in **YOUR** thoughts, even on the questions that ask about your partner. So please do not get any information or input from your spouse while filling out the questionnaire.
3. Please answer every question to the best of your ability, even if you are unsure of your response.

If you have any questions, please feel free to contact Genevieve Fitzgerald at 215-573-7275. Thank you in advance for your participation.

Date you are filling out this questionnaire: ____/____/____

- 1) Which of the following possible treatments for prostate cancer have you heard of (*check all that you have heard of*)?
- ☐ Surgery (Radical prostatectomy- procedure where they remove the prostate)
 - ☐ Radiation therapy
 - ☐ Seed implants (Brachytherapy)
 - ☐ Hormone therapy
 - ☐ Watchful waiting (No treatment, but getting regular blood tests to check on the status of the cancer)

- 2) Based on the information you have, what do you think your partner's chance of impotence is? (*Please give a number between 0% and 100%*). _____

- 3) Based on the information you have, please rate what you think your partner's chance of impotence is (*circle one number*):

1	2	3	4	5
Not at all likely	Slightly likely	Somewhat likely	Very likely	Extremely likely

- 4) Based on the information you have, what do you think your partner's chance of incontinence is? (*Please give a number between 0% and 100%*). _____

- 5) Based on the information you have, please rate what you think your partner's chance of incontinence is (*circle one number*):

1	2	3	4	5
Not at all likely	Slightly likely	Somewhat likely	Very likely	Extremely likely

- 6) Based on the information you have, what do you think your partner's chance of death is? (*Please give a number between 0% and 100%*). _____

- 7) Based on the information you have, please rate what you think your partner's chance of death is (*circle one number*):

1	2	3	4	5
Not at all likely	Slightly likely	Somewhat likely	Very likely	Extremely likely

- 8) Based on the information you have, what do you think your partner's chance of cure is? (*Please give a number between 0% and 100%*). _____

- 9) Based on the information you have, please rate what you think your partner's chance of cure is (*circle one number*):

1	2	3	4	5
Not at all likely	Slightly likely	Somewhat likely	Very likely	Extremely likely

Questions 10-15 ask about YOUR thoughts about different prostate cancer treatments and their possible side effects

- 10) How concerned are **you** about your partner experiencing incontinence (which is trouble controlling his urine)?

☐ Extremely concerned ☐ Very concerned ☐ Somewhat concerned
☐ Slightly concerned ☐ Not at all concerned

- 11) How concerned are **you** about your partner experiencing impotence (which is the inability to attain or maintain an erection)?

☐ Extremely concerned ☐ Very concerned ☐ Somewhat concerned
☐ Slightly concerned ☐ Not at all concerned

- 12) How concerned are **you** about your partner experiencing the risks of anesthesia (the medicine that they give to patients to put them to sleep during the surgery during which they remove the prostate)?

☐ Extremely concerned ☐ Very concerned ☐ Somewhat concerned
☐ Slightly concerned ☐ Not at all concerned

- 13) Which treatment do **you** think has the best chance of cure for your partner?

☐ Surgery ☐ Radiation therapy ☐ Hormone therapy
☐ Watchful waiting ☐ Seed implants ☐ I don't know
☐ They all have the same chance of cure

- 14) Which treatment do **you** think has the best chance of avoiding side effects?
- ☐ Surgery ☐ Radiation therapy ☐ Hormone therapy
- ☐ Watchful waiting ☐ Seed implants ☐ I don't know
- ☐ They all have the same chance of side effects
- 15) If it had been up to you, which treatment would you have chosen for your partner?
- ☐ Surgery ☐ Radiation therapy ☐ Watchful waiting
- ☐ Seed implants ☐ Hormone therapy ☐ Other (please explain):

Questions 16-20 ask about your thoughts about what your PARTNER thinks about different treatments and possible side effects. Please remember to respond without input from your partner.

- 16) How concerned do **you think your partner** is about experiencing incontinence (which is trouble controlling his urine)?
- ☐ Extremely concerned ☐ Very concerned ☐ Somewhat concerned
- ☐ Slightly concerned ☐ Not at all concerned ☐ I don't know
- 17) How concerned do **you think your partner** is about experiencing impotence (which is inability to attain or maintain an erection)?
- ☐ Extremely concerned ☐ Very concerned ☐ Somewhat concerned
- ☐ Slightly concerned ☐ Not at all concerned ☐ I don't know
- 18) How concerned do **you think your partner** is about experiencing the risks of anesthesia (the medicine that they give to patients to put them to sleep during the surgery during which they remove the prostate)?
- ☐ Extremely concerned ☐ Very concerned ☐ Somewhat concerned
- ☐ Slightly concerned ☐ Not at all concerned ☐ I don't know
- 19) Which treatment do **you think your partner** thinks has the best chance of cure for him?
- ☐ Surgery ☐ Radiation therapy ☐ Hormone therapy
- ☐ Watchful waiting ☐ Seed implants ☐ I don't know
- ☐ They all have the same chance of cure
- 20) Which treatment do **you think your partner** thinks has the best chance of avoiding side effects?
- ☐ Surgery ☐ Radiation therapy ☐ Hormone therapy
- ☐ Watchful waiting ☐ Seed implants ☐ I don't know
- ☐ They all have the same chance of side effects

- 21) How often did you and your partner discuss his treatment options? (*please circle a number below*)

1	2	3	4	5
Never	Seldom	Now and then	Quite often	Very often

- 22) Would you have preferred to discuss your treatment options more or less? (*please circle a number below*)

1	2	3	4	5
Much less	A little less	Neither more nor less	A little more	Much more

If you responded "never" to question 21, skip to question 26. Otherwise, continue to question 23.

- 23) When you had these discussions about treatment options, who initiated them?
☐ Me ☐ My partner ☐ We both initiated some of the discussions.

- 24) How satisfied were you with those discussions? (*please circle a number below*)

1	2	3	4	5
Very dissatisfied	Somewhat dissatisfied	Neither satisfied nor dissatisfied	Somewhat satisfied	Very satisfied

- 25) How often did you and your partner get into a disagreement or conflict over the issue of which treatment to choose? (*please circle a number below*)

1	2	3	4	5
Never	Seldom	Now and then	Quite often	Very often

The following statements focus on the way you deal with the fact that your partner has prostate cancer. Please indicate to what extent you do or do not act in the ways described.

	Never	Seldom	Now and then	Quite often	Very often
26) I try to discuss it with my partner openly	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27) I ask my partner how he feels	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28) When something bothers my partner, I try to discuss the problem	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29) I am full of understanding towards my partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30) I make my partner feel that he is not alone in this	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31) I try to persuade my partner to follow the doctor's instructions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32) I try to hide my worries about my partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

33) I try to act as if nothing is the matter	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34) I give in when my partner makes an issue of something	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35) I just wave my partner's worries aside	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
36) I do everything to prevent my partner from thinking about his disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
37) I can't endure my partner being concerned and act as if I do not notice my partner's worries.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38) I take over as much of my partner's work as possible.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

39) How strongly did you want your opinion to be factored into your partner's treatment decision? *(Circle a number below)*

1	2	3	4	5
Not at all	A little	Somewhat	Very	Extremely

40) How satisfied are you with the information you have about your partner's prostate cancer diagnosis and treatment options? *(Circle a number below)*

1	2	3	4	5
Very dissatisfied	Somewhat dissatisfied	Neither satisfied nor dissatisfied	Somewhat satisfied	Very satisfied

This last section asks a few questions about you.

41) What is your age? _____ years

42) What is your race?

☐ African-American
☐ Asian-American

☐ Caucasian ☐ Hispanic
☐ Other (please specify) _____

43) What level of education have you completed? *(Circle a number below)*

9	10	11	12	13	14	15	16	17	18	19	20	21+
high school				college				graduate school				

Thank you for your participation. Please mail the completed survey in the enclosed, stamped, addressed envelope.

Appendix D: Physician survey

Date ____/____/____

Patient name _____

Please fill out after telling patient of his positive prostate biopsy and his treatment options.

1) Did you recommend a particular treatment to the patient? ☐ Yes ☐ No (*If no, skip to #4*)

2) What was the recommendation (*check all that apply*)?

☐ Radical prostatectomy

☐ Radiation therapy

☐ Hormone therapy

☐ Brachytherapy

☐ Watchful waiting

☐ Other (Please explain):

3) How strong was your recommendation for this treatment option? (*check one option*)

☐ Not at all
strong

☐ Slightly
strong

☐ Somewhat
strong

☐ Very
strong

☐ Extremely
strong

4) Do you think the patient asked all of the questions that he had?

☐ Yes

☐ No

5) Did you suggest that the patient speak to a radiation oncologist?

☐ Yes

☐ No

6) How concerned do you think this patient is about:	Extremely	Very	Somewhat	Slightly	Not at all	I don't know
Impotence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Incontinence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Risks of anesthesia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7) Did you give the patient **information about each of the following** things using **numbers** (for example, "a 2% chance") or **words** (for example, "a very small chance")?

a) **Chance of impotence** (*check one option*)

☐ No numbers,
only words

☐ Some numbers,
some words

☐ Only numbers,
no words

☐ No information given about
chance of impotence

b) **Chance of incontinence** (*circle one option*)

☐ No numbers,
only words

☐ Some numbers,
some words

☐ Only numbers,
no words

☐ No information given about
chance of incontinence

c) **Chance of death** (*circle one option*)

☐ No numbers,
only words

☐ Some numbers,
some words

☐ Only numbers,
no words

☐ No information given about
chance of death

d) **Chance of cure** (*circle one option*)

☐ No numbers,
only words

☐ Some numbers,
some words

☐ Only numbers,
no words

☐ No information given about
chance of cure

8) Which best describes how the patient's treatment decision was made?

☐ I made the final decision

☐ I made the final decision after seriously considering the patient's opinion

☐ The patient and I shared responsibility for the final decision.

☐ The patient made the final decision after seriously considering my opinion.

☐ The patient made the final decision on the basis of the facts he learned from me and elsewhere, without considering my opinion.

☐ I don't know (because the patient made the decision with another doctor)

Appendix E: Patient information letter

Dear Sir,

We are writing to inform you of a study we are conducting a study to learn about patient decision making. The study involves a survey that we will mail to your home, with a stamped addressed envelope for you to return the survey to us.

We would like to ask you if you are willing to participate in our study. If you have a spouse or live-in partner, we would like that individual to fill out a survey as well. It is very important to us to get as many participants as possible. Your participation in this study is a unique opportunity for you to contribute important information that may help doctors to better assist future patients in making difficult decisions.

We will send you a survey in the next 2 months. If you do NOT wish to participate, please call Genevieve Fitzgerald at 215 573 7275. Choosing not to participate will not affect your medical care at the Veteran's Affairs Medical Center in any way. Feel free to also call this number if you have any questions about the study.

Thank you in advance for your participation.

Sincerely,

Bruce Malkowicz, MD
Department of Urology

Katrina Armstrong, MD
Department of Medicine